



NASET's Educating Children with Severe Disabilities Series

Comprehensive Overview of Intellectual Disability

What is Intellectual Disability?

Intellectual Disability is a term used when a person has certain limitations in mental functioning and in skills such as communicating, taking care of him or herself, and social skills. These limitations will cause a child to learn and develop more slowly than a typical child. Children with Intellectual Disability may take longer to learn to speak, walk, and take care of their personal needs such as dressing or eating. They are likely to have trouble learning in school. They will learn, but it will take them longer. There may be some things they cannot learn.

What Causes Intellectual Disability?

Doctors have found many causes of Intellectual Disability. The most common are:

Genetic conditions. Sometimes mental retardation is caused by abnormal genes inherited from parents, errors when genes combine, or other reasons. Examples of genetic conditions are Down syndrome, fragile X syndrome, and phenylketonuria (PKU).

Problems during pregnancy. Intellectual Disability can result when the baby does not develop inside the mother properly. For example, there may be a problem with the way the baby's cells divide as it grows. A woman who drinks alcohol or gets an infection like rubella during pregnancy may also have a baby with an intellectual disability.

Problems at birth. If a baby has problems during labor and birth, such as not getting enough oxygen, he or she may have intellectual disability.

Health problems. Diseases like whooping cough, the measles, or meningitis can cause mental retardation. Intellectual Disability can also be caused by extreme malnutrition (not eating right), not getting enough medical care, or by being exposed to poisons like lead or mercury.

Intellectual Disability is not a disease. You can't catch Intellectual Disability from anyone. Intellectual Disability is also not a type of mental illness, like depression. There is no cure for mental retardation. However, most children with Intellectual Disability can learn to do many things. It just takes them more time and effort than other children.

How is Intellectual Disability Diagnosed?

Intellectual Disability is diagnosed by looking at two main things. These are:

- the ability of a person's brain to learn, think, solve problems, and make sense of the world (called IQ or intellectual functioning); and
- whether the person has the skills he or she needs to live independently (called adaptive behavior, or adaptive functioning).

Intellectual functioning, or IQ, is usually measured by a test called an IQ test. The average score is 100. People scoring below 70 to 75 are thought to have mental retardation. To measure adaptive behavior, professionals look at what a child can do in comparison to other children of his or her age. Certain skills are important to adaptive behavior. These are:

- daily living skills, such as getting dressed, going to the bathroom, and feeding one's self;
- communication skills, such as understanding what is said and being able to answer;
- social skills with peers, family members, adults, and others.

To diagnose Intellectual Disability, professionals look at the person's mental abilities (IQ) and his or her adaptive skills. Both of these are highlighted in the definition of Intellectual Disability provided between the lines below. This definition comes from the Individuals with Disabilities Education Act (IDEA). The IDEA is the federal law that guides how schools provide early intervention and special education and related services to children with disabilities.

Providing services to help individuals with Intellectual Disability has led to a new understanding of how we define Intellectual Disability. After the initial diagnosis of Intellectual Disability is made, we look at a person's strengths and weaknesses. We also look at how much support or help the person needs to get along at home, in school, and in the community. This approach gives a realistic picture of each individual. It also recognizes that the "picture" can change. As the person grows and learns, his or her ability to get along in the world grows as well.

IDEA's Definition of "Intellectual Disability"

Our nation's special education law, the IDEA, defines Intellectual Disability as . . .

". . . significantly subaverage general intellectual functioning, existing concurrently with deficits in adaptive behavior and manifested during the developmental period, that adversely affects a child's educational performance." [34 Code of Federal Regulations §300.7(c)(6)]

How Common is Intellectual Disability?

As many as 3 out of every 100 people in the country have Intellectual Disability (The Arc, 2001). Nearly 613,000 children ages 6 to 21 have some level of mental retardation and need special education in school (Twenty-fourth Annual Report to Congress, U.S. Department of Education, 2002). In fact, 1 out of every 10 children who need special education has some form of Intellectual Disability.

What Are the Signs of Intellectual Disability?

There are many signs of Intellectual Disability. For example, children with Intellectual Disability may:

- sit up, crawl, or walk later than other children;
- learn to talk later, or have trouble speaking,
- find it hard to remember things,
- not understand how to pay for things,
- have trouble understanding social rules,
- have trouble seeing the consequences of their actions,

- have trouble solving problems, and/or
- have trouble thinking logically.

About 87% of people with Intellectual Disability will only be a little slower than average in learning new information and skills. When they are children, their limitations may not be obvious. They may not even be diagnosed as having Intellectual Disability until they get to school. As they become adults, many people with Mild Intellectual Disability can live independently. Other people may not even consider them as having Intellectual Disability.

The remaining 13% of people with Intellectual Disability score below 50 on IQ tests. These people will have more difficulty in school, at home, and in the community. A person with more severe Intellectual Disability will need more intensive support his or her entire life. Every child with Intellectual Disability is able to learn, develop, and grow. With help, all children with Intellectual Disability can live a satisfying life.

What About School?

A child with Intellectual Disability can do well in school but is likely to need individualized help. Fortunately, states are responsible for meeting the educational needs of children with disabilities.

For children up to age three, services are provided through an early intervention system. Staff work with the child's family to develop what is known as an Individualized Family Services Plan, or IFSP. The IFSP will describe the child's unique needs. It also describes the services the child will receive to address those needs. The IFSP will emphasize the unique needs of the family, so that parents and other family members will know how to help their young child with mental retardation. Early intervention services may be provided on a sliding-fee basis, meaning that the costs to the family will depend upon their income. In some states, early intervention services may be at no cost to parents.

For eligible school-aged children (including preschoolers), special education and related services are made available through the school system. School staff will work with the child's parents to develop an Individualized Education Program, or IEP. The IEP is similar to an IFSP. It describes the child's unique needs and the services that have been designed to meet those needs. Special education and related services are provided at no cost to parents.

Many children with Intellectual Disability need help with adaptive skills, which are skills needed to live, work, and play in the community. Teachers and parents can help a child work on these skills at both school and home. Some of these skills include:

- communicating with others;
- taking care of personal needs (dressing, bathing, going to the bathroom);
- health and safety;
- home living (helping to set the table, cleaning the house, or cooking dinner);
- social skills (manners, knowing the rules of conversation, getting along in a group, playing a game);
- reading, writing, and basic math; and
- as they get older, skills that will help them in the workplace.

Supports or changes in the classroom (called adaptations) help most students with Intellectual Disability. Some common changes that help students with Intellectual Disability are listed below under "Tips for Teachers." The resources below also include ways to help children with Intellectual Disability.

Tips for Parents

Learn about Intellectual Disability. The more you know, the more you can help yourself and your child. See the list of resources and organizations at the end of this publication.

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Encourage independence in your child. For example, help your child learn daily care skills, such as dressing, feeding him or herself, using the bathroom, and grooming.

Give your child chores. Keep her age, attention span, and abilities in mind. Break down jobs into smaller steps. For example, if your child's job is to set the table, first ask her to get the right number of napkins. Then have her put one at each family member's place at the table. Do the same with the utensils, going one at a time. Tell her what to do, step by step, until the job is done. Demonstrate how to do the job. Help her when she needs assistance. Give your child frequent feedback. Praise your child when he or she does well. Build your child's abilities.

Find out what skills your child is learning at school. Find ways for your child to apply those skills at home. For example, if the teacher is going over a lesson about money, take your child to the supermarket with you. Help him count out the money to pay for your groceries. Help him count the change.

Find opportunities in your community for social activities, such as scouts, recreation center activities, sports, and so on. These will help your child build social skills as well as to have fun.

Talk to other parents whose children have Intellectual Disability. Parents can share practical advice and emotional support.

Meet with the school and develop an educational plan to address your child's needs. Keep in touch with your child's teachers. Offer support. Find out how you can support your child's school learning at home.

Tips for Teachers

Learn as much as you can about Intellectual Disability. The organizations listed at the end of this publication will help you identify specific techniques and strategies to support the student educationally. We've also listed some strategies below.

Recognize that you can make an enormous difference in this student's life! Find out what the student's strengths and interests are, and emphasize them. Create opportunities for success.

If you are not part of the student's Individualized Education Program (IEP) team, ask for a copy of his or her IEP. The student's educational goals will be listed there, as well as the services and classroom accommodations he or she is to receive. Talk to specialists in your school (e.g., special educators), as necessary. They can help you identify effective methods of teaching this student, ways to adapt the curriculum, and how to address the student's IEP goals in your classroom.

Be as concrete as possible. Demonstrate what you mean rather than just giving verbal directions. Rather than just relating new information verbally, show a picture. And rather than just showing a picture, provide the student with hands-on materials and experiences and the opportunity to try things out.

Break longer, new tasks into small steps. Demonstrate the steps. Have the student do the steps, one at a time. Provide assistance, as necessary.

Give the student immediate feedback.

Teach the student life skills such as daily living, social skills, and occupational awareness and exploration, as appropriate. Involve the student in group activities or clubs.

Work together with the student's parents and other school personnel to create and implement an educational plan tailored to meet the student's needs. Regularly share information about how the student is doing at school and at home.

Resources

American Association on Mental Retardation. (2002). Mental retardation: Definition, classification, and systems of supports (10th ed.). Washington, DC: Author. (See contact information below.)

Baker, B., & Brightman, A. (with Blacher, J., Heifetz, L., Hinshaw, S., & Murphy, D.). (2004). Steps to independence: Teaching everyday skills to children with special needs (4th ed.). Baltimore, MD: Paul H. Brookes. (Telephone: 800.638.3775. Web:www.brookespublishing.com)

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Kaufman, S. (1999). Retarded isn't stupid, Mom! (Rev. ed.). Baltimore, MD: Paul H. Brookes. (See contact information above.)

Trainer, M (1991). Differences in common: Straight talk on mental retardation, Down syndrome, and life. Bethesda, MD: Woodbine House. (Telephone: 800.843.7323. Web:www.woodbinehouse.com)

Organizations

The Arc of the United States

1010 Wayne Avenue, Suite 650

Silver Spring, MD 20910

301.565.3842

Info@thearc.org E-mail

www.thearc.org Web

www.TheArcPub.com Web (Publications)

American Association on Intellectual and Developmental Disability (AAIDD)

501 3rd Street, NW Suite 200

Washington, DC 20001

202.387.1968; 800.424.3688 (outside DC)

www.aaidd.org Web

Division on Developmental Disabilities

The Council for Exceptional Children

1110 North Glebe Road, Suite 300

Arlington, VA 22201-5704

888.232.7733; 703.620.3660

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